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Family adjustment and interventions in neurodevelopmental disorders

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Abstract

Purpose of review—Developmental disabilities are increasingly recognized, and remarkable progress is being made on the genetic and neurobiological underpinnings of many disorders. Yet, only a tiny percentage of the disability literature addresses families of children with disabilities. A review of recently published family studies reveals salient trends and gaps.

Recent findings—Consistent with previous work, high levels of parent stress, illness, anxiety, and depression are apparent. Studies in the USA focused on parents of children with autism; in contrast, studies on parents of children with intellectual disabilities were almost always conducted abroad. Compared to other disabilities, families of children with psychiatric disorders and genetic syndromes are understudied. The majority of family studies are descriptive, with very few trials or interventions aimed at reducing parental stress. Of these, mindfulness practices and a peer-mentor model of treatment delivery hold much promise for effective stress reduction. Psychoeducational programs and respite care are differentially beneficial.

Summary—A new era of family intervention research is in order. This work can take advantage of many advances in telemedicine, peer-mentor models, smart technology, and biomarkers as indices of change. Benefit could also stem from group interventions with parents who share similar concerns, regardless of their child's diagnostic label.

Keywords

developmental disabilities; families; intervention; mindfulness; stress

INTRODUCTION

Let there be no doubt that raising children with intellectual or developmental disabilities (IDDs) is challenging and stressful, with potentially significant health and mental health consequences for parents. At the same time, new studies confirm that raising these children also leads to a profound sense of meaning, purpose, and personal growth, including a renewed sense of patience, purpose in life, and gratitude. Parenting children with

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Conflicts of interest

None.

developmental disabilities can subsume all of these experiences over time, or in the course of a moment. But it is chronic stress and distress that gets under the skin, leading to physiological changes and increased vulnerabilities for physical illness, psychological distress, and psychiatric disorders [1].

The literature describing parental adjustments to raising children with developmental disabilities spans decades; here we focus on recent studies published over the past 2 years. A literature search using Web of Science revealed a large number of studies on how parents are faring. After reviewing them for content and ruling out studies that focused solely on children or other issues, 173 pertinent publications were ascertained. These are far too many to individually review, yet large enough to identify meaningful trends and gaps.

TRENDS IN THE 2012–2014 INTELLECTUAL OR DEVELOPMENTAL DISABILITY FAMILY LITERATURE

Plenty of publications focus on ‘individuals’ with developmental disorders. Indeed, using the same search engine and process of weeding out irrelevant hits noted above (Table 1) shows the large number of studies on individuals with autism spectrum disorders (ASDs) or psychiatric disorders relative to those with other developmental disorders.

Individual versus family studies in developmental disabilities

In contrast to studies on ‘individuals’, however, only a very small percentage of literature over the past 2 years has focused on ‘families’ of offspring with developmental disabilities. Table 1 shows the numbers and percentages of family articles across five different groups: autism, intellectual disabilities, other developmental disabilities, genetic syndromes, and psychiatric disorders. On the basis of the total number of studies in each diagnostic group, family studies capture, on an average, just 3% of published work in these disorders.

The uneven distribution between individual versus family studies is both predictable and unsettling. On the one hand, technological advances are facilitating a remarkable growth of new insights into the genetic and neurobiological mechanisms of many specific IDD [7]. Such work requires increasingly specialized expertise and technology, as well as interdisciplinary research that enable linkages between neurobiological, genetic, developmental, and phenotypic data.

On the other hand, this remarkable progress appears to be accomplished at the expense of studies on the families in which affected individuals live and grow. However, two qualifications to this assertion are in order. First, while families are certainly studied, it is typically through the lens of parental risk factors that potentially contribute to child outcomes. Such studies focus, for example, on parental genetic or epigenetic contributions, or other factors (e.g. age, infections, and exposures during pregnancy) that may have a causal link to offspring with developmental disabilities.

Second, a body of critically important work has examined children living in adverse, toxic, or impoverished families or institutions, providing unique insights into brain plasticity, stress, and developmental trajectories [8]. Research on extreme environmental conditions,

including children exposed to abuse, violence, or neglect, points to actionable risk factors and social policies that can improve outcomes for all children, including those with developmental disabilities.

Genetic factors and extreme family or environmental conditions aside, what do the 173 family studies noted in Table 1 address?

Reoccurring findings and themes in recent family studies

The 173 recently published articles generally affirm previous work showing considerable stress in parents of children with disabilities, and at much higher levels than parents of typically developing children. These articles differentially address one or more of the following themes:

1. **Maternal coping and mental health:** These include maternal emotional, problem-solving, avoidant and other coping styles, as well as anxiety, depression, sleep, optimism, hope, satisfaction, health, mental health, well-being, broader autism phenotype in parents or siblings.
2. **Family demographics and quality of life:** These typically encompass parental age and ethnicity, cultural factors, social networks and family services and supports, family cohesion, stigma, self-stigma, and family isolation.
3. **Economic resources:** Hardships, poverty, and employment status may be studied, along with long-term fiscal impacts on the family or society at large.
4. **Marital relationships:** Variables here include divorce, spousal closeness, warmth, support, and marital satisfaction.
5. **Child factors:** These generally include child diagnosis, behavior or emotional problems, autism symptoms, age, communication skills, functional impairments, prognosis, and for adult children, where they reside.

The majority of the 173 family publications (64%) applied the themes noted above to parents of children with ASD. As shown in Table 1, remaining articles were equally spread between intellectual and developmental disabilities, with fewer studies on families of children with genetic syndromes or psychiatric disorders.

Several factors likely contribute to the predominance of studies on families of children with ASD. Certainly, the rising prevalence of children diagnosed with ASD, now approximately 1% of the child population [2], partially explains these trends. As well, there continues to be considerable federal and private foundational funding for research on ASD relative to other disabilities. Studies on the broader autism phenotype in first-degree relatives could also inflate study numbers, but just four of the 110 family autism studies addressed this issue.

The predominance of family studies in autism is consistent with a recent analysis of which neurodevelopmental disorders get studied. Bishop [9] found that both National Institutes of Health (NIH) funding and publications favored rare, clinically severe conditions. However, two prevalent disorders were major exceptions to this rule – autism and attention deficit

hyperactivity disorder? – with each showing substantial increases in funding and publications.

While a research and funding focus on rare, clinically severe disorders may apply to affected ‘individuals’, this trend does not appear to hold up in studies of ‘families’ of affected individuals. Indeed, very few recent studies examined the families who care for children with psychiatric disorders, genetic syndromes, or severe intellectual disabilities [10].

Consistent with current practices, family studies often used the global term ‘developmental disabilities’ to describe their samples with heterogeneous causes. Although the Tables aimed to represent each disorder as distinctly as possible, diagnostic overlap exists. As such, these Tables should be viewed as painting broad strokes of the family literature. For example, the 22 family studies in developmental disabilities included those with sensory, motoric, or medical disabilities who may or may not have also had co-occurring cognitive impairments.

Historically, the prevalence rate of intellectual disabilities has varied between 1 and 3%, with a recent international meta-analysis reporting intellectual disabilities in 1% of the population [3]. Thus, even though intellectual disabilities are as prevalent as ASDs, disproportionately fewer studies focused on the concerns of parents raising children with intellectual disabilities as opposed to ASD. Bishop [9] noted a similar trend in the literature, albeit with individuals, not families, in which publications on intellectual disabilities fell below the level predicted by either the prevalence or severity of these disabilities.

International trends in family studies

The majority of studies on families of children with intellectual and developmental disabilities were conducted abroad. As shown in Table 2, just one study on families of children with intellectual disabilities was conducted in the USA, and 18 abroad. In contrast, families of children with autism accounted for 80% of family studies published in the past 2 years. Studies abroad were better distributed across disability types, with autism being a focus in 40% of international family studies.

Probing these findings further, 24 different countries contributed to the past 2 years of family and disability literature. Australia, the UK, and Canada collectively accounted for 44% of international family publications, and 17% were from India, China, or Greece. The remaining 39% originated from countries that varied considerably in their levels of economic development. Overall, then, researchers in the USA are more likely to publish study families of children with autism than families of offspring diagnosed with other developmental disabilities.

GAPS IN THE 2012–2014 INTELLECTUAL OR DEVELOPMENTAL DISABILITY FAMILY LITERATURE

The vast majority of studies on families of children with developmental disabilities are descriptive in nature. Across different samples, countries, measurement tools, and even decades of time, data consistently show that families are stressed and distressed, with variations noted in expected directions based on the themes described above.

Intervention studies

Having thoroughly described families, we now need to translate this work into meaningful interventions that help families. Strikingly, however, Table 3 shows that just 20 articles (11%) of the 173 family publications over the past 2 years were devoted to interventions aimed at reducing parental stress or enhance their well-being. An additional four articles outlined therapeutic models to guide future intervention [11]. Intervention studies were only included in this tally if there was some measure of parental outcome; not included were studies that provided parent training in order to impact specific child outcomes. Sometimes, however, parent training that targets child functioning may also have indirect or downstream salutatory effects on parent stress [12]. Articles that formally measured such indirect effects were counted among the 11%.

The types of interventions tested in these 20 studies are summarized in Table 4. Of note is that the vast majority of interventions were psychoeducational in nature. These approaches generally combined teaching, modelling, or sharing specific disability-related information (e.g. transitioning youth with ASD, behavior problems in young children), with additional curriculum on parent coping skills or tips for stress reduction [13[■],14–16]. Psycho-educational groups were generally effective, with participants reporting more parenting confidence and emotional support and, at times, reduced stress.

Three of the 20 intervention studies assessed the impact of respite care on families [17[■], 18[■],19]. These studies report positive effects, including improved marital relations and less distress after taking a welcomed reprieve from care giving duties. A concern, however, is that these short breaks do not necessarily teach parents new skills or strategies to promote their healthy development once the break is over. Good responses to marriage or family counseling were also reported in couples with children on the autism spectrum [20]; however, just a few case reports and theoretical issues were described.

An additional three studies took a different approach by implementing groups of mindfulness-based stress reduction with parents of children with autism and other disabilities [21[■],22,23[■],]. The salutatory effects of mindfulness practices have a strong evidence base, and are increasingly used in medical and psychiatric patients, educational settings, and in the general population. Two of these studies used a wait list control design [21[■],22], and one also included special education teachers – a group at high risk for professional burn out [22]. The third study – a randomized trial of 243 mothers – compared mindfulness-based stress reduction to positive psychology interventions aimed at promoting healthy adult development [23[■]].

At post-treatment, all three mindfulness studies reported improved parental outcomes in stress and depressive symptoms, and one [21[■]] noted modest spill over effects of parental improvements on children's ADHD symptoms. The comparative effectiveness study [23[■]] also followed participants up to 6 months after treatment. On average, improvements were sustained in the post-treatment follow-up period in sleep, well-being, stress, depression, and anxiety. Further, whereas both treatments had positive effects, those in the mindfulness group showed steeper and more rapid improvements, and those in the positive adult development arm reported increased well-being during follow-up.

The comparative study also successfully tested a peer-mentor model of treatment delivery [23[■]]. Prior to co-leading treatment groups, parents of children with disabilities went through in-depth training in intervention curricula, research ethics, and the peer-mentor role; they also received clinical supervision throughout the study. This approach took advantage of naturally occurring rapport between parents in the disability community, and showed considerable promise for reaching at-risk families who may not otherwise seek professional services.

Psychiatric disorders

Strikingly, less than 1% of recent studies of children with psychiatric disorders addressed the stress, adjustment, and coping of parents raising these children. This gap is an important one to fill. Parents of children with psychiatric disorders face similar challenges as parents of children with autism or other IDD. These include managing significant child behavioral or emotional problems, advocating for their child, organizing medical, behavioral and other therapies, coping with stigma and isolation, and oftentimes, continuing their direct care giving role with adult children. Just one intervention study of parents of children with psychiatric illness was conducted in Eastern Asia [24[■]]. Positive effects of empowering parents and rejecting stigma were found but tempered somewhat by cultural views and expectations. It is puzzling that family genetic or epigenetic contributions to psychiatric illness are of keen research interest, whereas parental stress and challenges in caring for these children are understudied, including interactions between stressful households and disease expression.

Siblings

Although the sibling literature is gaining momentum, researchers often overlook these family members. Indeed, just 2% of the family studies reviewed addressed the adjustment of siblings living with a brother or sister with developmental disabilities. Even so, siblings have increasingly important care-giving roles as the population of adults with disabilities ages, and parents are no longer able to assume care-giving roles. Two recent studies of siblings of brothers or sisters with schizophrenia identify key elements that propel siblings to or from a care-giving role [25[■],26]. Other work found lower than expected levels of anxiety in siblings of brothers or sisters with autism [27[■]], and several beneficial effects of family respite care for siblings [17[■]].

Biomarkers of stress

Only a handful of family studies have used bio-markers to index levels of stress and distress in parents of children with disabilities. Disturbingly, these parents show blunted diurnal cortisol trajectories [28[■],29], accelerated telomere shortening [30], and compromised immune function in response to vaccination [31]. All are indices of stress chronicity. These and other biomarkers should be used to complement parental self-report as outcomes in future trials or interventions.

CONCLUSION

Future studies are urgently needed that translate descriptive literature on heightened stress, illness, and psychiatric problems in parents of children with developmental disabilities into effective interventions. Indeed, one would be hard pressed to think of another descriptive family study that needs to be done in autism in order to conduct such interventions.

This is an ideal time to usher in an exciting new era of family interventions that take advantage of advances in telemedicine, smart technology, or social media; the promise of trained peer mentors to deliver interventions; and the insights provided by neural, hormonal, and other biomarkers as indices of treatment response. More inclusive thinking is also warranted about shared family stressors and needs for treatment that cut across child diagnostic labels. Such a new era of work shines a light on a role that is both instinctual and challenging for professionals and families alike – taking care of others in ways that also enrich ourselves.

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KEY POINTS

- Studies on family functioning comprise a very small percentage of the literature on developmental disabilities.
- Family studies are predominantly descriptive and underscore the high risk of parents raising children with developmental disabilities for stress, health, and mental health problems.
- In the USA, most studies on disabilities and family functioning focus on autism, whereas studies abroad are more inclusive of other developmental disabilities.
- Effective parent interventions such as mindfulness practices, short breaks, or psychoeducational programs need to be more widely disseminated and evaluated, perhaps through networks of trained peer mentors.

Table 1

Number and percent of recent research articles on individuals versus families, by disability type

	Estimated prevalence ^a	Articles on affected individuals ^b	Articles on family life	% of family to individual articles	% of all family articles
Autism spectrum disorders [2]	1%	3114	110	3%	64%
Intellectual disabilities [3]	1%	111	19	17%	11%
Developmental disabilities [4]	6%	102	22	22%	13%
Genetic IDD syndromes [5]	.05	416	11	2%	6%
Child psychiatric disorders [6]	19%	2304	11	<1%	6%
Total		6047	173	3%	100%

^aPrevalence estimates were derived from references for each disorder. The developmental disabilities estimate was calculated from the study by Boyle *et al.* [4] using a 2006–2008 prevalence rate of 15.04% for any disability, and removing their prevalence estimates for intellectual disabilities, autism and attention deficit hyperactivity disorder? which are captured in other categories in Table 1. Similarly, the numbers of developmental disabilities articles excluded autism, intellectual disabilities or genetic syndromes, as these were noted elsewhere in the table.

^bFor all articles, numbers only included research articles and excluded reviews, abstracts and editorials. ADHD, attention deficit hyperactivity disorder; IDD, intellectual or developmental disability.

Table 2

Number of 2012–2014 family studies conducted in studies in the USA versus abroad

	Family studies conducted in the USA	Family studies conducted abroad
Autism spectrum disorders	81	29
Intellectual disabilities	1	18
Developmental disabilities	9	13
Genetic syndromes	5	6
Child psychiatric disorders	5	6
Total	101	72

Table 3

Number of family descriptive versus intervention studies published between 2012 and 2014, across disability types

	Descriptive family studies	Family intervention studies	Family intervention theories
Autism spectrum disorders	110	11	3
Intellectual and developmental disabilities	41	8	0
Genetic syndromes	11	0	0
psychiatric disorders	11	1	1
Total	173	20	4

Table 4

Distribution of types of family interventions across disability groups

Types of family intervention	Autism spectrum disorders	Intellectual, developmental disabilities	Psychiatric disorders	Total
Psychoeducational, support	5	5	1	11
Marriage or family therapy	3	0	0	3
Respite care, short breaks	2	1	0	3
Mindfulness-based stress reduction	1	2	0	3
Theory, models, recommendations	3	0	1	4
Total	14	8	2	24